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No. 3

Care experiences and home care preferences

amongst older Travellers and older people experiencing homelessness

A briefing paper based on the Older Traveller and Older Homeless (OTOH) study.

Institute for Lifecourse and Society

Building a Better Health Service
Seirbhís Sláinte Níos Fearr á Forbairt

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Disclaimer:
Facts and opinions expressed in this Briefing Report are solely that of the Irish Centre for Social Gerontology (NUI Galway) and the research team, and are not necessarily those of the Health Service Executive and the Department of Health. The Health Service Executive and the Department of Health are not responsible for any use that may be made of the information contained in this study.

Why is this topic important?

In Ireland, in recent years, there has been a coordinated effort to improve the design, consistency, and quality of home care services for older people, with the aim of enshrining the rights to, and regulation for, these services within legislation (IPH, 2018; Keogh and O'Shea, 2020; Oireachtas, 2020). While these developments are particularly welcomed, there is a need to ensure any new home care reforms are accessible and relevant to the most marginalised of older populations. Older members of the Traveller community and older people who have experienced homelessness are two such groups who are more likely to encounter health inequalities, poor health outcomes, and exclusionary barriers to accessing health and social care services (Cush *et al.* 2020).

Home and community care models have gained particular prominence as a service structure that respects the dignity and diversity of older people, and marks a general shift internationally towards ageing-in-place strategies (Panni-Harreman *et al.* 2020; Urbaniak and Walsh, 2020; Sixsmith and Sixsmith, 2008). A concentrated policy focus on ideas related to positive health and ageing has in part driven this shift (Walker and Maltby, 2012; O'Shea, 2006). De-institutionalising care and allowing people to grow old in the security of their own homes, and in their own communities, is considered to be a fundamental step in promoting equity and choice for ageing populations (WHO, 2008).

However, the voices of older Travellers and older adults who have experienced homelessness are frequently absent from health policy and practice development (Smyth, 2016). Given the potential complexity of their care needs, and the propensity for accumulated social exclusions (Cush *et al.* 2020), accounting for the views and care requirements of these groups in re-developing home support services is essential. It is also essential to ensure an equitable ageing society that is reflective of policy goals to combat unequal ageing (OECD, 2017) and to provide *'the right to affordable long-term care… in particular home-care and community-based services'* (Principle 18, European Pillar of Social Rights (European Commission, 2019)). In addition, as both older adult Travellers and older people who have experienced homelessness are at risk of displacement from traditional, permanent home environments – around which home care frameworks are developed (Grenier *et al.* 2016) – specific efforts are likely to be required to apply home care schemes to these populations.

What is the purpose of this Briefing Report?

This Briefing Report investigates the experiences of older Travellers and older adults who have experienced homelessness in using health and social care services, and establishes their needs and preferences with respect to home care delivery. The Brief will also highlight barriers as identified by members of these communities in accessing appropriate home care provision. The Briefing Report draws on findings of the Older Traveller and Older Homeless (OTOH) study to present the views and perspectives of these sections of the older Irish population. First, a short overview of the methodology used to collect and analyse the data will be outlined, including a summary of the backgrounds and demographics of the study participants. Second, findings related to current experiences of using health and social care services are presented. Third, the sources of support and home care are described and, fourth, barriers in accessing formal home care provisions are outlined. Fifth, findings related to participants' needs and preferences for home care delivery are presented. Finally, conclusions are drawn from these findings, and key policy recommendations are presented.

This is the third Briefing Report from the OTOH Briefing Report Series. For more information on the series and the OTOH study, please go to **https://icsg.ie/our-projects/otoh/**.

About the Older Traveller and Older Homeless (OTOH) Study

The aim of this study is to investigate life-course and structural determinants of positive subjective health amongst older Travellers and older people who have experienced homelessness, with a view to centralising the voice of these groups in effective, ethical and rights-based models of home care delivery. This programme of work has five objectives:

1. Review international knowledge on determinants of positive health, in community contexts, for vulnerable groups of the older population;
2. Explore social and primary care provision for older Travellers and older individuals who have experienced homelessness in Ireland, identifying individual- and structural-level risk factors for health inequities, informal practices for addressing such disparities, and on-the-ground knowledge deficits;
3. Capture the lived experiences, expectations and needs of a diverse group of older Travellers and older individuals who have experienced homelessness, unpacking the role of individuals' life events, and societal and institutional practices in the construction of positive health biographies;
4. Facilitate and advance the voice of older Travellers and older individuals who have experienced homelessness to highlight 'insider' perspectives on meanings of home and successful strategies for securing positive health biographies;
5. Harnessing learning from older Travellers and older individuals who have experienced homelessness, develop policy recommendations to inform the development and implementation of relevant and impactful older adult home care structures.

What did we do?

The data presented in this Briefing Report was collected using a qualitative, 'voice-led' methodology, which was participatory in approach and designed to place the voice of older Travellers and older people who have experienced homelessness at the heart of this study.

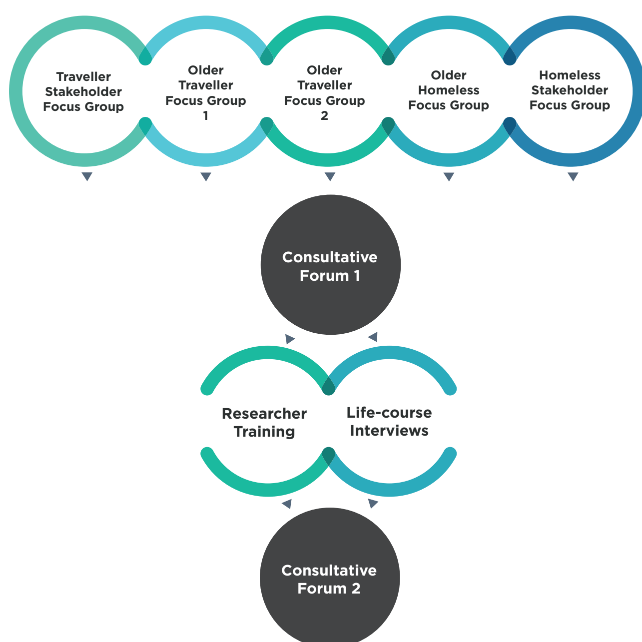

Figure 1: Primary data collection strands

With reference to Figure 1, the study involved five data-collection strands. First, to investigate the challenges, opportunities and inequities encountered by the two groups, five focus group discussions were conducted separately with: older homeless people (n=5); older adult Travellers (two groups; n=11 overall); and statutory and third-sector stakeholders working with and representing older homeless adults (n=7), and older adult Travellers (n=7). These stakeholders included representatives from public and third sector social care providers, primary and community health care organisations, and national advocacy and civil society groups. Second, a Consultative Forum (n=9), which drew together a sample of participants from each focus group was conducted to confirm the focus group findings, and to agree the priority research questions to be investigated in subsequent strands. Third, in-depth life-course interviews were conducted with 22 older adult Travellers (8 male; 14 female) and 27 older homeless people (22 male; 5 female) (n=49 overall). Interviews lasted approximately one hour and consisted of three parts: an open narrative portion which focused on a single question about health experiences; an in-depth, semi-structured portion based on questions and topics agreed in the Consultative Forum (for example meanings and behaviours related to positive health and ageing; community and societal belonging; utilisation, needs and preferences for community-based health and social care services); and two life-path exercises where participants worked with the researcher to map out (1) their health biography of positive and negative experiences (Figure 2), and (2) their residential history over their lives (Figure 3).

The interviews were audio-recorded and transcribed before being analysed with the aid of *NVivo* qualitative analysis software. Fourth, five older individuals (either Travellers or those who had experienced homelessness) were trained as participant researchers, and conducted their own research projects (in the areas of identity and belonging, and health and social care environments and service delivery) with the support of the OTOH study team. Fifth, the Consultative Forum was reconvened for the purpose of reviewing the overall findings from the study, and agreeing priorities and recommendations for policy and practice (n=9).

All participants were either older ethnic Irish Travellers or older adults who are currently, or who have recently experienced homelessness. Reflecting the faster pace of biological ageing that both groups face, 'older' was defined in this study as those aged over 50 years. Consideration in recruitment was also given to age, gender, housing and accommodation status, urban or rural location, health status, ethnicity, and for older homeless participants, duration of homelessness (for more details on interviewee demographics, see Tables 1 and 2). Reflecting the diversity of participants, the social care needs of the study sample ranged from those who did not need any form of assistance (with some individuals even serving as informal carers for others) to those who possessed complex and multifaceted care needs. The majority of the field research took place in 2019 and early 2020, in sites on the East and West coast of Ireland (primarily Dublin, and Galway cities and counties). The second Consultative Forum was conducted online in December 2020, due to the COVID-19 pandemic.

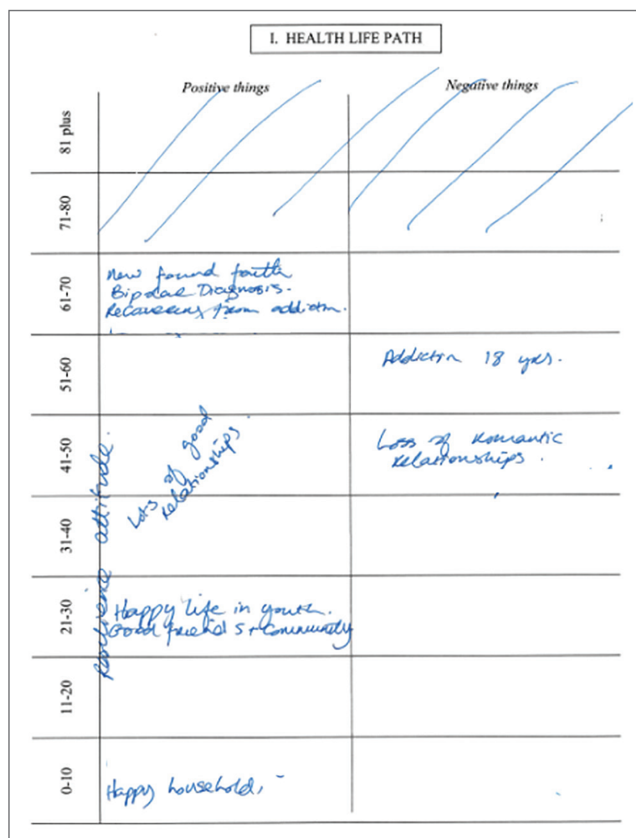

Figure 2: Sample of completed health life path

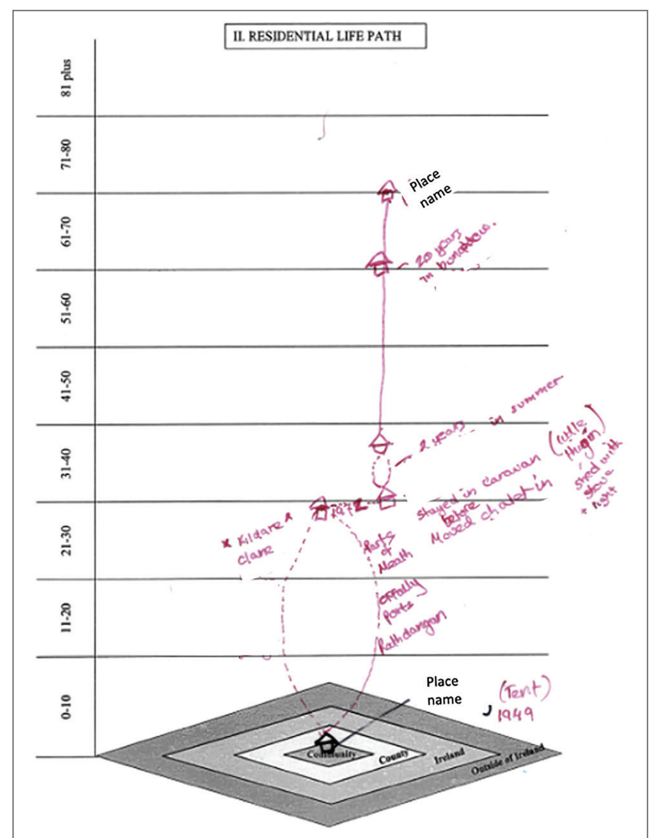

Figure 3: Sample of completed residential life path

Gender	Male	Female
	8	14

Age	50-54	55-59	60-64	65-69	70-74	75-80	No data
	9	1	4	5	2	0	1

Marital status	Married or partner	Separated/divorced	Single	Widowed	No data
	16	2	1	2	1

Accommodation type (Traveller)	Group housing or halting site	Local authority housing	Private rented accommodation	Unauthorised temporary location	Home owner	No data
	12	7	0	0	2	1

Main employment class	Professional	Managerial or technical	Non-manual	Skilled-manual	Semi-skilled	Unskilled	No data
	0	0	6	4	2	9	1

Level of educational attainment	No education	Incomplete primary	Completed primary	Completed group, inter or junior cert	Completed leaving cert or equivalent	Post leaving cert diploma	Third level degree or higher	No data
	2	6	9	2	1	1	0	1

Table 1: Older Traveller interviewees' demographic information

Gender	Male	Female
	22	5

Age	50-54	55-59	60-64	65-69	70-74	75-80
	3	11	5	6	2	0

Marital status	Married or partner	Separated/divorced	Single	Widowed
	3	13	9	2

Accommodation type[1]	Sleeping rough (roofless)	Houseless (temporary accommodation)	Insecure accommodation	Inadequate accommodation	Secure accommodation
	0	24[2]	0	0	3[3]

Temporary accommodation type (n=24)	Emergency accommodation	Long term accommodation	Supported accommodation	Supported community housing
	8	5	9	2

Main employment class	Professional	Managerial or technical	Non-manual	Skilled-manual	Semi-skilled	Unskilled
	0	0	6	4	2	9

Level of educational attainment	No education	Incomplete primary	Completed primary	Completed group, inter or junior cert	Completed leaving cert or equivalent	Post leaving cert diploma	Third level degree or higher
	2	6	9	2	1	1	0

Table 2: Older homeless interviewees' demographic information

[1] ETHOS classification
[2] See next two rows for further breakdown
[3] Homeless charity facilitated independent housing (n=2); Private rented accommodation (n=1)

Although all strands of work have informed the conclusions of this study, it is the data from the in-depth interviews with older adult Travellers and older homeless people that are primarily presented in this Briefing Report. However, where appropriate this information is supplemented with data from the focus group discussions with older people and sector stakeholders. The conclusions and recommendations presented in the Briefing Report also reflect the discussion of the second Consultative Forum.

How is Positive Health Described in Research?

Positive subjective health can be understood as a complex cognitive process, which incorporates physical health and functional ability, subjective bodily feelings, internal (coping mechanisms and resilience) and external resources and mental and psychological well-being (Benyamini, 2011; Idler and Benyamini, 1997; Ryff and Singer, 1998).

What did we find?

Experiences of health service utilisation

Interviewees' generally reported positive experiences with the formal health system. Many participants highlighted at least one service, or health care relationship, that was influential in their lives (see Briefing Report no. 2 in this series for further details). Accounts focused on: not having to wait long to be assessed or treated in outpatient and primary care clinics; being facilitated access to further health services when needed; and the kindness with which services were provided. Several participants also noted the effectiveness with which diagnoses and treatments were communicated:

When the doctor is telling me stuff, I can understand, because she's knows us very well…There'd be no big words or anything like that… and I find the Chemists now are gone the same way.
(BCTD8: Traveller participant, female, 51)

The Primary Health Care for Travellers Projects (PHCTP) (for older Travellers) and keyworkers and homeless residential services (for older adults experiencing homelessness) were particularly highlighted as facilitating these positive experiences by helping to identify need, and promoting and connecting participants to key health services.

Evidence of negative experiences were, however, also apparent and were explicitly mentioned by over a quarter of participants. A number of individuals from both groups highlighted experiences of perceived discrimination when accessing services, linked to being a Traveller, or someone who was experiencing homelessness:

As soon as they hear you're homeless…You're not being admitted… [to hospital]… I fell asleep one day when I was there. I was very sick, very sick…the security nudged me and woke me up. 'Come on'. I said, 'I'm a patient.'… [He said]… 'I don't care, come on.'
(BCHD24: Homeless participant, female, 50)

Stakeholders working with older Travellers and older homeless adults recounted similar examples that highlighted the occurrence of these experiences amongst their client base. As this stakeholder describes, these instance can be particularly damaging:

An older person can be very much entrenched in homelessness. So, when they present to a hospital their ailment or their perceived ailment is very important to them because they are homeless, and they have come in from a homeless hostel maybe in an ambulance, or with staff support. They really are kind of, they are not treated in a positive fashion you know, they come back unseen sometimes because they are left waiting 12 hours in an emergency department when they really could be seen quite quickly…
(Homeless stakeholder focus group participant)

Challenges often centred around the accessibility of health services. For members of both groups, a lack of awareness of entitlements and services sometimes remained an issue, whereas for others it was based on the lack of availability of affordable or accessible transport to attend appointments:

I have problems if I had to go to Galway now or into the eye clinic with my eyes or anything like that, I would have to pay for taxis going in and out… €100 in and out… [I have to pay]…
(BCTG7: Traveller participant, female, 51)

Participants also faced difficulties in accessing specialised services, for example substance dependence treatment. For several adults experiencing homelessness, and some older Travellers, access issues were compounded by not having a permanent address. Where an older adult experiencing homelessness was not yet connected to a service keyworker, these access challenges were far more problematic as she wasn't aware of her welfare entitlements, leaving her lacking in the financial resources to maintain her health and well-being in other ways:

My depression was still huge for me, but since I went to my sister the other day now I do feel a lot better… she knows me better than anyone… we just ended up talking, then she ended up doing a lovely dinner, we were doing the washing and then she done a makeover on me… I was meant to go up to her today to collect all the rest of my washing and all but I haven't got the bus fare.
(BCHD24: Homeless participant, female, 50)

Participants also reported communication problems in attempting to use formal services. These barriers could result from low levels of general or health literacy, cultural differences (in the case of the Traveller community), perceived power imbalances and, as was the case for some older Travellers living in halting sites, the absence of postal services to deliver medical appointment notifications. This participant describes how such issues can sometimes converge to prevent access to required supports:

There are other Travellers out there that are not accepted by doctors or don't get the help and support they need because they can't read and write… And then they're discriminated by the hospitals or doctors because they're missing their appointments. And if they miss two appointments, they won't get another one… And postmen around here don't go into sites… So, you don't get your letters.
(BCTD19: Traveller participant, female, 53)

Sources of support and home care

Of those who required support, three participants were currently in receipt of formal home care services. The majority of other participants who required support did not express the need for formal home care provision, and instead received care from other sources. Informal care played a significant role in many people's lives. For older Travellers, this involved supports provided mainly by relatives and immediate family members who assisted in a variety of different tasks. This included personal care and household chores, and provided support in accessing formal health care, particularly when literacy was an issue.

For older homeless adults, while some participants reported receiving help from siblings, it was homeless service volunteers, keyworkers, and other personnel (often connected to charitable and third-sector organisations delivering accommodation services) who were mostly described as providers of care and support. These activities often appeared to be outside the role of these individuals, or at least to be stretching the official remit of some services. Participants described assistance with daily tasks, finding information on services, filling out forms, and, as this participant describes, accessing and attending medical appointments and follow-up services:

I had to go to the doctor and… [a key worker]… said she'd drive me… and when I went in there I got the letter to go to James's [hospital] and she brought me back here, got my clothes and drove me to James's. (SKHD5: Homeless participant, male, 68)

However, for both older Travellers and older homeless adults, concerns were expressed by participants and service stakeholders that these sources of support were increasingly under strain, and unlikely to be sustainable. Stakeholders particularly talked about the range and complexity of care needs that some members of these populations could possess, and how these sources of support may simply not be sufficient. In the case of Traveller family care givers, the level of care was often thought to be too physically or psychologically burdensome for family members. As the first-hand experiences of this older woman caring for her terminally ill husband indicate, such circumstances can have serious consequences for the family member's health:

He [husband] wouldn't allow anybody to give him his shower only me… But then… I had a heart attack myself back in 2013 and I died for about 35 minutes… he was too heavy for… [me]… to keep lifting, bringing him in and out to the shower and dressing him.
(SKTD19: Traveller participant, female, 61)

Nonetheless, there can be considerable pressure from others in the Traveller community to continue to provide care in the face of such challenges, as this stakeholder describes:

Also some families would be, I don't know whether it's ashamed or fear, to avail of the home help because the extended family have huge pressure on them, saying, 'Why can you not look after that person'.
(Traveller stakeholder focus group participant)

In the case of older homeless adults in residential services, while social care supports were provide by some homeless service personnel, the demand for and intensity of these supports, could place staff under significant pressure. This means that care for (often vulnerable) individuals may not always be as consistent, or as comprehensive as it needs to be. It was also reported by homeless stakeholders that such supports could extend beyond the remit of services to include aspects of nursing and health care. These issues are particularly acute when it comes to requirements for specialised forms of support, such as end-of-life care, and when access to specialised older adult care facilities is not provided:

We have people who are in beds that we can't get into hospital or into palliative care… they are left for their end of days with ourselves… no way is that dignified… amongst staff who don't have the skills… acting essentially way outside their areas and stuff and that puts an awful strain on the staff as well.
(Homeless stakeholder focus group participant)

Barriers to accessing home care

There was evidence of bureaucratic and structural barriers in accessing formal home care services for both groups. First, it was highlighted that older Travellers and older individuals who had experienced homelessness can fall through gaps in the system due to their demographic profile, and circumstances. This again reflected the complexity of care needs, particularly around advanced biological ageing, multi-morbidity, cognitive impairment and mental health issues, and dual and complex diagnoses, that require integrated care approaches. But it also related to age and disability eligibility criteria for personal care schemes. One statutory stakeholder, who coordinates support services for these populations, describes how this can lead to ambiguity around entitlement, potential unmet need, as well as fragmented provision across Community Healthcare Organisations:

It's the luck of the draw, depending on what area you live in… If you're in a disability service, you apply to a disability manager for a package; if you're over 65 you apply for an older person's disability package. But the people we're dealing with, who are homeless and they're maybe in their late 50s or 60s, or Traveller persons who are presenting older… they come to us. But they need the service and you can't just say, 'the computer says no'. There is no official screening from area to area.
(Traveller stakeholder consultative forum participant)

Second, it was perceived these communities were often left to their own devices because of an assumption that family will always care for older Travellers, and homeless services will provide care for older homeless adults. For example, in the absence of a sufficient care package, one homeless residential service manager spoke of having to refuse to accept residents back into the facility when they were to be released from hospital with complex needs. This resulted in these older individuals having to remain in hospital as stigmatised 'bed blockers' until satisfactory provisions could be made for their care.

Third, the appropriateness of some of the residential environments of both population groups for home care provision was also raised as a barrier (for more on material circumstances as a structural barrier to health and well-being, see Briefing Report no. 2 in this series). One Traveller participant, who lived in a mobile home, highlighted how her living circumstances were not suitable as a site for care, due to fall hazards, and accommodation size and quality:

If you're living in a house you get loads of care all right, but not [in a mobile home]…When I have surgeries I go into respite… I have no other choice… Out of my home, but I could have been back in my home if I had had a right home, but I had to be kept in respite because I had a drain in for six months.
(BCTD18: Traveller participant, female, 66)

Concern was also expressed that homeless residential facilities were neither designed to be care environments, nor sufficiently equipped for later life health and mobility needs - even when home care supports were being provided within these facilities. These environments could sometimes undermine the fundamental ethos of care provision, and the personhood of individuals:

There isn't the number of single rooms, mobility access, disability access, toilets… They're just not there… there are just no beds and everybody is just lumped in together. That's quite a brutalising experience I think. It certainly strips any sense of individuality from it. It's production line care.
(Homeless stakeholder focus group participant)

Yet, homeless service stakeholders also spoke about how even when other care options are available some older people can be reluctant to leave the accommodation having grown attached to the service and the setting.

One of the significant issues that we would have is… where some of the people in our high-support housing would be there for a prolonged period of time and when their care needs go beyond what we're able to provide in a social care setting and really they need more nursing home type care and they adamantly and vehemently do not want to leave our service…
(Homeless stakeholder focus group participant)

Preferences for home care

Participants discussed preferences for home care across four dimensions.

Awareness and Access
At a fundamental level, several participants spoke about the significant need to enhance awareness of home care supports amongst the two communities, reflecting their continued level of disconnection from some aspects of the health and social care system. This was firstly in terms of providing accessible information and knowledge of entitlement on the services involved in home care supports:

I would say that's in lots of areas you know there is home help there, but lots of Travellers that we know… we've a few elderly people… that don't avail of home help… you have different services within the local area … and we wouldn't know that they're… [the services]… actually there but it's kind of letting people know that they are there.
(Traveller stakeholder focus group participant)

Secondly, participants highlighted the need for assistance in accessing home care provisions. This was related to low levels of health and general literacy, as well as a lack of familiarity with the bureaucracies of health and social care systems. Thirdly, it referred to the need to build an understanding amongst older Travellers and older adults who have experienced homelessness of the ways that such services are relevant to their lives, and often necessary for ageing members of their communities. Some participants acknowledged a reluctance to accept formal services because of the lack of recognised need and the fear of losing independence:

We have a man down the road here… and he's 90. And he'd decided no one will go into his house… .He wouldn't allow homecare… He does his own food. He does everything… He thinks now that he doesn't need it. But I think he does, and his family thinks he does.
(KWSKTD3: Traveller participant, male, 52)

Approach to delivery
Participants spoke about the need for home care services to be sensitive to and orientated towards the circumstances of both groups. This included being mindful of the sorts of life experiences encountered by these individuals, the impact of stigmatisation, the cultural needs of older Travellers (with respect to religious beliefs and family), the effects of low levels of literacy on an individual's capacity to advocate for their own care needs:

My own father is 91 and he is in a nursing home but he won't question anything… He won't challenge it, and it's like that with a doctor, a priest or a guard. They were seen as the people in authority. Particularly with a Traveller person… that may not be able to read or is not going to understand what they're saying. They're just going to accept it, you know.
(Traveller stakeholder focus group participant)

Older participants suggested training should be provided so that care professionals have a better understanding of 'where we're coming from', and know how to communicate appropriately. Interviewees emphasised the need for treating service-users equally, with respect and dignity, and without prejudice, regardless of their background, age or level of care needs.

Given the depth of disadvantage and trauma that characterised the lives of some members of these groups, interviewees also spoke about the need for proactivity in following-up with participants, after they've been diagnosed with a health condition or prescribed a course of treatment:

But, yeah, as far as this thing here, medical and all, you nearly have to put things in the laps of people like us before we believe that people really care about us. We're too lost in our losses. And I'm speaking personally. Too lost in the losses.
(SKHD7: Homeless participant, male, 59)

Range of services
The range of services that should be included in home care packages was also discussed. Participants spoke about the need for the services that are typically included in home care packages. These included those framed as core instrumental supports such as assistance with personal care (for example bathing and hygiene; dressing) and household activities (for example cleaning and meal preparation). Participants also emphasised services that would address specific needs, and more profound deficits, relating to their own circumstances.

A number of interviewees focused on relational aspects of care delivery, and pointed to the continued absence of emotionally supportive relationships, and a sense of connectedness, in some people's lives. This was particularly raised by older people who had experienced homelessness. For this reason, and to circumvent issues of loneliness and isolation, it was suggested a part of home care services must be based on providing meaningful human interaction:

I think it would be excellent just for to have home care just so people have someone to talk with. You know… human interaction, no matter what it is… The loneliness is the killer… I definitely think though anything to avoid the loneliness.
(BCHD1: Homeless participant, male, 68)

Several participants spoke about how accommodation and residential security should be a part of, or at least a prerequisite for home care delivery. Participants focused on the perceived links between stable and good quality housing, and health and well-being, but also the need for a safe and hazard free environment in which to receive care. For others, the focus was on aspects of dignity and privacy which were enabled by appropriate accommodation, and core to care provision:

You have to have your own place where you can bring in your own friends, rather than being in… a hostel...but until such time as you regain privacy, my own place...you're lost, that's my feeling.
(Homeless service-user focus group participant)

In a similar manner, several participants conveyed how home care delivery should encompass other roles and functions that would be more enabling in nature. One participant suggested that home carers could support the development of house-keeping skills, if this is something a service-user had never had the opportunity to learn. This reflected the desire to learn additional self-care skills, but also how in the case of some older adults who had experienced homelessness, they may need to transition through different accommodation types, and need to be supported in doing so. This is described by one stakeholder:

People that have been in homeless services since they were quite young and now they're at that older age… The fear of if they move on to live on their own, they've never had that, you know, so it's the fear of moving and not being in a service… that's a huge fear if somebody has spent most of their life in services…
(Homeless stakeholder focus group participant)

But in the main, participants focused on how home care workers should direct older adults to wider sets of services and resources that they may need, and advocate for or broker access to same. This was reflective of the diversity and range of needs that some individuals had, and that despite current supports, the task of identifying and accessing these services in the current systems may be overwhelming. It also reflected the lack of integration and coordination of some services required by some members of these communities, such as housing and literacy supports:

So it's very important and we all work closely together like MABS and Irish Traveller Movement, Pavee Point and the primary healthcare projects because look it when you look at Government they're bringing in policy and if you look at a lot of policy they bring in sometimes they don't think of the people it's going to impact mostly on. (Traveller stakeholder focus group participant)

Home care workers

Finally, participants focussed on who should deliver home care. Interviewees in both groups noted the fundamental need for carers to be kind, patient, and friendly. Within participants' descriptions it was clear, however, that it was establishing trust that was considered a central pillar around which an effective care relationship could develop. This was also echoed by stakeholders who had experience of delivery supports to these communities:

If you go in and you're watching the clock and you've got 10 minutes and you're trying to tell someone they need to do this, this and this… I just think you need to give it more time but I think if you gave it the time, people are really curious and they'll ask you every question inside their mind if they trust you like… It's having trust and a lot of Travellers don't trust the services that are available.
(Traveller stakeholder focus group participant)

In line with this, reliability was emphasised as a core quality of a home care worker. For older Travellers, there was a lack of consensus on whether or not a carer should be someone from the Traveller community. Some participants felt a carer from the settled population may provide a greater sense of privacy, given the highly connected nature of Traveller society. However, many more participants felt that Traveller home carers would ensure that a cultural understanding was embedded within the care relationship:

You need to have Traveller carers… and you understand where they're coming from and what helps and supports that they need. And you can communicate better because they'll listen to you quicker than they'd listen to someone else.
(BCTD19, Traveller participant, female, 61)

What are our conclusions?

This Briefing Report presented findings on the experiences of older Travellers and older homeless people in using health and social care services, and on their needs and preferences for home care delivery. The research shows that although positive experiences were reported by many participants, gaps in care remain for these populations, exposing challenges to positive health and ageing. In part, these gaps reflect broader sets of challenges with respect to home care delivery for older people in Ireland, including the dominance of informal provision, the fragmentation of statutory-funded services and the lack of coordination across agencies (O'Shea *et al.* 2019). But these gaps also stem from the groups' marginalised position in society – manifest as physical, social, material and psychological disadvantage – and a systemic failure to account for the need for more equitable care provision. The role of institutional and structural barriers in shaping earlier life experiences that have detracted from good health, and that have set up negative well-being outcomes in later life, cannot be overlooked (also see Briefing Reports nos. 1 and 2 in this series). Nor can we rule out how low expectations, as a result of being unsupported for extended periods, may influence older Travellers' and older homeless adults' levels of satisfaction with care.

The findings have also demonstrated the significant efforts, particularly at grass-roots level, to address these gaps. The roles of the Primary Health Care Traveller Projects, homeless organisations and residential services, local authority workers, and a range of Health Service Executive (HSE) agencies and staff (such as public health nurses, and social inclusion officers) were all evident in this regard. Certainly, without the work of these individuals and organisations, the welfare and well-being of the two populations would be more at risk. The agency of individual older Travellers and individuals who have experienced homelessness must also be recognised in how they have negotiated health and well-being challenges. The value of local and sometimes informal cross-sector relationships, multi-agency working and good-will has emerged strongly in this research – and based on anecdotal evidence has been particularly crucial since the advent of the COVID-19 pandemic. But further prioritisation and resourcing is required if this strong commitment to serve these two groups is to be sustained, coordinated, and truly impactful. A more active transversal consideration of the situations of older Travellers and older homeless adults is also needed across the sectors

working with and for older people, the Traveller community, and homeless populations. While valuable examples of this cross-sector consideration are certainly evident (Gibney *et al.* 2018), a richer cross-pollination of agendas should be encouraged – particularly amongst those charged with developing and executing policy initiatives and pursuing advocacy goals within each sector.

The research illustrates that the implementation of any planned reforms to home support services must attend to the circumstances of these two populations. The needs and preferences of older Travellers and older people who have experienced homelessness for home care delivery extend beyond traditional home care packages and approaches. However, they remain in line with the principles espoused within the proposed Professional Home Care Bill (independent living; privacy and dignity; quality of care; protection), and other suggested models of new home supports for older adults (Keogh and O'Shea, 2020). Nevertheless, home care for these groups requires an enhanced sensitivity to the individual circumstances of older Travellers and older homeless adults, and the sorts of inequalities that they have faced throughout their lives. It also needs to include a more flexible range of services that reflect the sort of complex and diverse needs that these groups can possess. To secure better positive health and ageing outcomes for these populations, supports must be well-communicated, free of stigmatisation and discrimination, and must target both the instrumental provision of care, and the enablement of individuals. In this respect, the Primary Health Care Traveller Projects and the role of the keyworker in homelessness services, may provide some valuable learnings in how they broker and enable for such supports.

Home care provision for these groups must account for and address the environmental insecurity that they can experience – housing deprivation amongst older Travellers, and the complete absence of private accommodation for older homeless adults. Environmental circumstances should not prevent the delivery of home care to older members of both of these communities, and in essence should be orientated to nurture the fundamentals of a sense of home, including belonging, control, privacy and centredness (Rowles, 2008). Additionally, as a part of the delivery of home supports, commitments must be made to actively improve the security of circumstances, and ultimately provide adequate and good quality private accommodation. Building on existing efforts, cross-departmental (with respect to policy) and HSE and local authority (with respect to practice) collaboration is critical here to address the combined health and environment deprivations of these groups.

Moreover, the research points to not only the influence of life-course experiences and risks on later-life health amongst older Travellers and older homeless adults, but also the potential for premature ageing – as previous public health and epidemiological studies have shown (e.g. Kiernan *et al.* 2020; Sullivan *et al.* 2018; Fazel *et al.* 2014). Eligibility criteria for home care supports should not as such be tied to a fixed chronological age threshold, or a narrow life-stage view of old-age. If a more flexible, life-course and early-intervention approach is not taken, older Travellers and older homeless adults will always fall within the cracks in the system. Risks and needs will only accumulate further and create greater distance between individuals and positive health and ageing outcomes. Whether sitting outside ageing specific home support services, or serving as a strand within, there is an opportunity under the Professional Home Care Bill to specifically attend to the needs of long marginalised groups, such as these. But, as per universal proportionalism, to do so at *"a scale and intensity that is proportionate to the level of disadvantage"* they have encountered (Marmot *et al.* 2010).

It is difficult to talk about home care for older Travellers and older homeless adults without acknowledging the significant deprivations across civil, economic, social and cultural rights (with respect to adequate housing, health, and equality of treatment) that can intertwine for these populations. Certainly, there are questions as to the extent to which the State is meeting its obligations under the personal rights provisions of the Irish Constitution and the European Convention on Human Rights Act 2003 for these two groups. There are, however, other rights-based considerations that are relevant at the level of practice that should also be applied to the circumstances of older Travellers and older homeless adults. The 'Public Sector Duty', stipulated in section 42 of the Irish Human Rights and Equality Commission Act 2014, requires all public bodies, including the HSE and local authorities, to eliminate discrimination, promote equality of opportunity and treatment, and protect human rights through the performance of their functions. It is imperative that these duties are now fulfilled for older Travellers and older homeless adults. In that regard, it is hoped that this research can help inform the Duty implementation process of 'assess', 'address' and 'report' on the issues faced by these two groups. A concerted effort is now required to ensure that future care provisions, and home support services, help to address the deprivations for older Travellers and older homeless adults, and not compound and create further challenges to positive health and ageing for these growing populations of Ireland's ageing society.

Recommendations

With reference to Figure 4, based on the findings of the research, we make recommendations in seven key areas to secure more equitable care provision and home support services for older Travellers and older adults who have experienced homelessness:

Figure 4: Key areas in securing equitable care provision and home support services

Relevant and Integrative Care Values

1. Under the forthcoming Professional Home Care Bill 2020, the provision of statutory funded home support services, and intensive home care packages, for older Travellers and older homeless adults and other marginalised groups of older people must be enshrined within new home care reforms, and promoted as a viable and accessible support regardless of the environmental and housing circumstances or tenure of these individuals. In this respect, organisations representing older Travellers and older homeless adults should also be encouraged to become members of The Home Care Coalition.

2. The diversity of needs, and the variety of circumstances and backgrounds, within the older Traveller and older adult homeless populations requires a publicly mandated adoption of a holistic person-centred approach to care and support that is grounded in an understanding of shared and individual life experiences, and that shifts the focus from a 'one-size fits all' view. This approach should be underpinned by consideration of gender, ethnicity, sexuality, disability and other aspects of diversity for these populations in relation to service design, delivery and monitoring and reporting.

3. Initiatives designed to respond to the need for further integration across the care-chains of these population groups (acute, primary and social care), for example the health inclusion service/hospital discharge programme/integrated assessment and care planning, should be supported and expanded where necessary by the HSE to continue supporting the development of comprehensive and collaborative multi-agency care plans, and to address cross-sector coordination challenges and service fragmentation.

4. The HSE, local authorities and other public sector bodies need to commit to fulfil their Public Sector Duty to older Travellers and older people who have experienced homelessness, in relation to eliminating discrimination, promoting equality and protecting human rights in the provision of appropriate care and accommodation.

Meaningful Co-production, Agency and Voice

5. Building on work linked to health inclusion and Public and Patient Involvement, establish older Traveller and older homeless adult reference panels, and develop guidelines to centralise their voices, in the design and co-production of programmes and processes (communication, training, and care pathways) related to their care.

6. Civil society and advocacy organisations from across the ageing, homelessness and Traveller community sector, should work with older members of these populations to instigate intersectional rights and equality agendas in relation to their health and well-being, giving voice to their concerns and supporting their engagement in advocacy and civic expression.

Training and Education for Inclusive Care

7. Prioritise the further development of user-informed training and education programmes on marginalised ageing populations for all actors within the care supply chain, including home care providers, to promote understanding of the context of people's lives and to eliminate the stigmatisation of these groups. This is to complement some of the work already underway within the sector.

8. Support services for Traveller informal carers should be strengthened through statutory funding to alleviate carer burden and to assist in fostering acceptance of formal home care services, and, where desired, Traveller people should be facilitated to undertake training in social care delivery, and supported by the HSE, Quality and Qualifications Ireland, Education and Training Boards Ireland and relevant NGOs to pursue a career as home care professionals.

9. Personnel and staff in homelessness charities and residential services should be given the opportunity where desired, and supported by the HSE to undertake training with respect to specific forms of social care delivery, or more specialised skill-sets with respect to palliative and end of life supports, for older populations.

Enabling and Flexible Home Supports

10. Home care support services need to be underpinned by a principle of enablement that supports the agency and development of older Travellers and older homeless adults, and where possible works to address entrenched forms of disenfranchisement and exclusion to build a stronger capacity for positive health and ageing.

11. To reflect the potential for complex needs, higher rates of co-morbidities, and broader sets of physical, mental and social health deficits amongst these groups, statutory funded home support services must incorporate a greater degree of flexibility, and integration of primary and social care, with respect to the supports provided for older Travellers and older homeless adults.

12. Ensure access to appropriate long-term care, including palliative and end-of life care to older adults in homeless residential services.

Meaningful and Secure Environments

13. Broadening the conception of home beyond simply that of the dwelling, and in line with the principles espoused within the new Professional Home Care Bill 2020, embed the goal of promoting a sense of home that instils feelings of belonging, privacy and security within the provision of home support services for these populations.

14. Further efforts are required to integrate the group residential settings of older Travellers and older homeless adults (e.g. group housing and halting sites; emergency and supported accommodation) into their local surrounding environments, reinforcing that these residents and places are a part of, and not a part from, our communities and neighbourhoods.

15. In recognition of the enabling role that accommodation can play in care delivery and positive health and ageing experiences, and to combat the negative impacts of substandard and insecure settings, the HSE and local authorities should work in collaboration to integrate comprehensive home development packages (and where desired residential relocation) with home support services for older Traveller and older adults experiencing homelessness.

Inclusion-Orientated Communication

16. Led by the HSE National Healthcare Communication Programme (NHCP) in collaboration with the National Adult Literacy Agency, care related-communication for these groups must be structured around appropriate content (accessible and culturally sensitive language), flexible communication modes (oral, visual, as well as written material) and proactive follow-up strategies (involving multiple support contacts; emphasising adherence), and underpinned by user-informed training for coordinators, administrators and care professionals.

17. To improve service awareness, and tackle stigma in accessing formal care services, outreach campaigns should be implemented by the HSE and third-sector representative organisations, to inform older Travellers and older homeless adults of: their entitlements to home support services; the services involved in home care; and the potential benefits and relevance these services may hold for their needs and circumstances.

Equitable Implementation and Monitoring

18. Reflecting the influence of life-course experiences and risks on later-life outcomes, and the potential for premature biological ageing, eligibility criteria for home support services should not be tied to a fixed chronological age threshold, or a narrow life-stage view of old-age, and instead should be based on need.

19. Underpinned by statutory regulatory and monitoring frameworks, private, voluntary, and public nursing homes and home care providers should develop care and support protocols targeting marginalised and diverse older populations, including older Travellers and older people who have experienced homelessness. These protocols need to account for gender, ethnicity, sexuality and disability and other aspects of diversity for these populations, and should inform the design, delivery and monitoring and reporting of services accordingly.

20. Any development and implementation of a home care regulatory framework, as proposed within the forthcoming Professional Home Care Bill, must include outcome indicators related to integration and inclusion, in addition to care quality and health and well-being, in the monitoring and assessment of the effectiveness of home support services for these population groups.

It is outside the scope of this Briefing Report to assess the budgetary implications of the recommendations presented here. Bodies such as the Irish Government Economic and Evaluation Service might usefully reflect on this dimension of the undertaking. Nonetheless, this paper, and the others in this series, marks an initial effort to examine the complexity of securing equitable positive health and ageing experiences for older Travellers and older people who have experienced homelessness. It demonstrates that a radical shift in the framing of these populations, and a fundamental re-orientation of the mainstream system, is required before such equity is in view. It is hoped that the research findings presented here demonstrates the need for this shift and re-orientation, and that the recommendations help to provide the necessary impetus and direction.

About the Older Traveller and Older Homeless Populations

In this study, older adult Travellers refer to those aged 50 years and over '...*who are identified...[by themselves and others]...as people with a shared history, culture and traditions including, historically, a nomadic way of life*' (Equal Status Act Ireland, 2000, Sec 2 (1)). While the majority of Irish Travellers live in private dwellings, only 20% own their own homes (versus 67.6% of the general population) and 3.2% live in caravans or other mobile or temporary structures (CSO, 2016). A series of restrictions on camping and mobility introduced in the early to mid-1960s greatly limited the travelling lifestyle, but while the majority of the population are no longer nomadic, nomadism continues to be a vital part of Traveller culture (Joyce, 2018). The Traveller population are also considered to have experienced systemic societal discrimination and long-standing marginalisation from mainstream societal institutions (education; health services; labour market). Currently, there are 2,639 older Travellers resident in Ireland (and a further 10,374 resident in England and Wales). The age structure of the Traveller community is significantly younger than the general population (aged 65 or older: Travellers, 2.5%; wider population, 13%). However, in line with increasing life-expectancy and reflecting international patterns for other indigenous populations, the older adult section of this community is growing (CSO, 2016).

Adopting the European Typology of Homelessness and Housing Exclusion (ETHOS), older adult homelessness in this research is considered to involve those aged 50 years and over who are currently or who have recently experienced rooflessness, houselessness, or who currently or have recently had inadequate or insecure accommodation (Amore *et al.* 2011; Edgar *et al.* 2003). There are 1,069 older homeless adults in Ireland with people aged 50 or older representing 15% of the total homeless population (CSO, 2016). However, due to difficulties in collecting accurate data, this is likely to be an under-estimation of the number of people experiencing later life homelessness. In line with demographic ageing patterns nationally, the older homeless population is expected to increase in size in the coming years, as it has in other nations. Internationally, the impact of economic uncertainty, the restricted supply of affordable housing, and ageing demographic structures have led to a marked increase in ageing homeless populations, with some jurisdictions – for example USA and Canada – reporting that up to half of the homeless group are aged 50 years and over (Grenier *et al.* 2016; Woolrych *et al.* 2015).

Older Travellers and older adults experiencing homelessness are more likely to experience poor health outcomes, a greater prevalence of co-morbidities, substantially lower healthy-life expectancies, and in some instances premature biological ageing (O'Donnell *et al.* 2016).

COVID-19 and Older Travellers and Older Homeless Adults

The Covid-19 pandemic has brought new challenges for the health of these two groups. The HSE Social Inclusion office anticipated this as a particular challenge for Travellers and developed supplementary guidance for this group as well as identifying priorities for their care during the pandemic (HSE Social Inclusion, 2020b). This is reflective of Travellers, and indeed homeless people being identified as two (of six) populations which are vulnerable to Covid-19 outbreaks. While homeless populations have represented less than 2% of all vulnerable group outbreaks, Travellers have accounted for almost 73% of vulnerable population Covid-19 outbreaks (HSE-HPSE, 2020).

While not focusing specifically on older members of the two groups, the National Social Inclusion Office reports on homeless and Traveller service user experiences during the pandemic illustrate that a significant minority (20%-34%) felt that their physical and mental health, as well as their quality of life was worse than at the same time the previous year. However, it is important to note that some of those homeless participants who had been cocooning or self-isolating reported a positive change in their health and well-being due to improvements in their living situation (for example having their own room) which were catalysed by the circumstances of the pandemic. These participants described positive changes around feelings of safety, mental health, drug use and relationships (HSE Social Inclusion, 2020a). In addition, some Traveller respondents reported accessing new health supports since the start of the outbreak including those for Covid-19 but also beyond (HSE Social Inclusion, 2020b).

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